

Founded in 1989

The Post-Polio Support Group of Orange County Newsletter

15231 Marne Circle
Irvine CA 92604

Website: ppsupportoc.org

May 2012

Last two months of Fund Drive for Orange County and Rancho PPS Support Groups

We hope not to bother you about money for another three to four years, if all goes according to plan. If you haven't donated yet and can afford to do so please send your check to **Polio Survivors, 12720 La Reina, Downey CA 90242.**

No one is required to make a donation to receive our newsletters. However, all readers must confirm that they want the newsletters by one of 3 ways:

- **Phone**
Marte Fuller **562-697-0507**
Marilyn Andrews **714-839-3121**
- **Email**
Rancho PPSG@hotmail.com
editorbaldwin@ppsupportoc.org
- **Standard Mail**

Polio Survivors, 12720 La Reina, Downey, CA 90242

Should we use our limited resources to mail to survivors who show no interest in continuing getting the newsletters???

Inside this Issue

<i>Fund drive draws to a close</i>	<i>Pg 1</i>
<i>Dr. Perlman speaks May 20th</i>	<i>Pg 1</i>
<i>Impact of Polio in US</i>	<i>Pg 1 - 6</i>
<i>Questions for Dr. Perlman</i>	<i>Pg 7</i>
<i>Support Group Info</i>	<i>Pg 7</i>
<i>Meetings</i>	<i>Pg 8</i>

Dr. Susan Perlman



**Sunday
May 20th
2pm -- 4pm**

Dr. Perlman administers the clinic for post-polio syndrome at UCLA. Many in our support groups have gone to her for our initial post-polio syndrome evaluation. Others see her for complexities arising out of PPS. She has been willing to communicate her recommendations to our primary care physicians and local specialists. Dr. Perlman has often repeated that, if polio survivors had only one medical special to select, it should be a Physical and Rehabilitation Physician (Physiatrist). Below you will find an outstanding presentation by an physiatrist with whom Dr. Perlman participates in furthering the work of *Post-Polio Health International*. Dr Vandernakker administers a very active post-polio clinic at UC Davis. Please read her thoughts to prepare for Dr. Perlman's visit. • NOTE CHANGED LOCATION!

Impact of Polio in US

Carol Vandenakker, MD

Presentation to **San Francisco Bay Area Polio Survivors** September 18, 2010

Transcribed by Phyllis A. Hartke

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INTRODUCTION

I've been thinking about how polio and PPS have impacted individuals, society, country and medicine. I contacted Dr. Lauro Halstead who has written a lot of articles and books about PPS and is a polio survivor. In the book

Continued on Pg 2 Col 1

“Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome”, 2nd edition, that he edited is a chapter he wrote about the lessons and legacies of polio. He gave me permission to use the ideas offered in that chapter.

Two things sparked my interest in this fascinating concept. An historian at UC Davis is thinking of writing a book about the impact polio and the polio epidemics had on the country, the development of the United States. Her mother is a polio survivor. Probably within the next year she'll be starting her research and maybe coming with me to the group and will be talking with you. Another reason for wanting to do more of an historical or life impact perspective on polio is that I lost this year to cancer my sister-in-law, a couple of years younger than me. It really hit home about just how fragile life is, how things can change so suddenly. We all need to make the most of the time we do have and look at what's happened to us in life, how it has impacted us and how we use that to impact other people.

Just having had polio, you all have already impacted society and this country and other people and medicine to a great extent. I want to talk a little about the societal perspective and then have you talk about your experiences and how your life has been impacted whether it is positive or negative.

SOCIETY IMPACT

Polio has been around for centuries. It shows up in ancient Egyptian art. What's interesting is that society was unaware of it as a problem until the late 1800's when improved sanitation brought on the polio epidemics. Before improved sanitation, children were exposed to the polio virus in their early childhood years. Polio was in the environment and most kids were exposed while they still had immunity from their mom and developed immunity. There were scattered cases of polio but not

these huge epidemics which started in Europe and the United States where there was the most development and best sanitation.

The first half of the 20th century with its polio epidemics was a unique period of time. This caused a lot of attention to be brought to disease processes and how they occur. In 1908 the polio virus was identified. It was the first time someone determined virus could cause human disease. Also rare was polio vaccine efforts.. It was the first time there was such a push to have development of a vaccine and people being aware of vaccines being able to prevent disease.

Eradication efforts were sponsored by the World Health Organization (WHO). Small pox is the only other disease that has been eradicated. It was easier to eradicate than polio which we are still working on. Wild polio is still in West Africa and the Indian subcontinent areas. Good news is that in the first half of 2010, only 254 cases of polio were reported. There have been several outbreaks of vaccine derived virus, meaning the virus from the vaccine has gotten out into the population and caused polio.

The younger generation has no recollection of the fear the public had of the polio epidemics. It could strike anybody, usually during summertime but it could be at other times of the year. Because of its oral fecal transmission, the polio virus often was in the water supply or pools or lakes and people came in contact with it when swimming or participating in water activities.

The polio virus does not survive below a certain temperature. After the first chill the virus dies in that area but there can still be virus in areas where it doesn't get that cold. That's part of the reason that it's possible to completely eradicate the virus. Once it's not in people for awhile it won't continue in the environment. Unfortunately, even if we completely eradicate polio, the virus can be replicated (grown) and

used for biological or germ warfare.

Polio was unlike a flu epidemic or the whooping cough which is making a comeback this year. Not only did polio cause death but also a number of children were ending up with paralysis and significant disabilities that impacted the rest of their lives. Even if you survived you weren't always unscathed.

The fact that Polio affected primarily children also contributed to the fear. Some people are often callous and don't care too much about what happens to older people but children mostly everybody cares about. This was the thrust for the strong push to find a cure for polio. The most recent example of a push for a cure and treatment of disease is when AIDS was discovered because it was so deadly when it first appeared. But AIDS did not cause the same level of panic in the population because there were certain ways for contracting AIDS and certain behaviors to avoid so you're not at risk. It's not just random that anybody could get it, like polio.

Also, polio was the first time the government gave a lot of support in dealing with disease. Money poured into the polio crisis, searching for a cure and providing treatment for children affected. Shriners Hospitals were a big part of that. Their mission's main focus was orthopedics, providing primary care and rehabilitation for polio children. Kids who did not have polio but had similar diseases and neurologic disorders that caused paralysis also benefitted. Some were mislabeled purposely as polio so they could get the care and benefits because there wasn't that kind of resource available for people who had other diseases.

What's interesting is that now you polio survivors have moved into that category of "other disease" which is not as well known or a big concern. You're seeing how hard it often can be to get appropriate help when you have a more

unaware condition. I think that has had a huge impact on polio survivors because you went from being the focus of the country, the society, as we pushed to conquer polio, and then when the vaccine came out, "ok, we did it. We're done." That's an abrupt change. It's like "we've done everything to help you. Then, "OK. We served you." But obviously not. The residual paralysis remained as did your struggle with function and getting around and doing things. And then we have the PPS decline over time. Nobody expected that. It's not a big deal to the general public now because nobody's worried about getting it. So it's a very interesting shift in focus and how you're viewed by the general public.

In medical education now you rarely hear about polio. It's mentioned as one of these past diseases and epidemics that used to occur. If you're lucky it is mentioned as a neurologic condition that still exists for people who are left with paralysis, but that isn't even always taught to medical students. For years textbooks all said it was a static condition. You had polio and were left with weakness, but that's it. You've adjusted to that. That's how you are going to be for the rest of your life. There's nothing more to worry about. Of course you all know that's not true.

Polio also contributed to what is common now as the commercialization of a disease or disability. Regarding public ads like "Let's Fight Muscular Dystrophy", "Let's Fight Cancer", polio was the first disease to blaze that trail of having a poster child making people aware and what is needed for treatment. Cute kids just a little bit disabled, often girls, were chosen. You were the poster child famous for 15 minutes and then forgotten. "OK, you served this purpose" and then nobody followed through.

Disabled people in this country in the first half of the 20th Century didn't have many rights at all.

People who were ill or had particular diseases were isolated, separated from society. Polio people got placed in polio hospitals. Many were shipped off, away from your families for months at a time. Families could not visit often if at all. Other examples of people being packed away separate from society are mental hospitals and leprosy colonies. The whole West society meant well with what they did with people who had any sort of medical condition that was either contagious or residual disability.

Polio survivors were the driving force behind disability rights. Individual polio survivors, not post-polio support groups, drove the whole legislation to establish independent living facilities and gain rights and help pass the ADA so there's public access to places even if you do have a disability or mobility challenge. They were in politics lobbying for change for people with disability and pushed for the ADA. It was a polio survivor who came up with "universal design" in designing buildings and equipment that all could use. The conveniences of curb cuts and modifications that now help the elderly rose from that.

There were quite a few survivors in society. Because of polio we had a larger section of society that lived with disability. Prior to the development of ICUs and respirators and other critical care equipment, people with spinal cord injury usually didn't survive. That secondary disability group didn't really appear until later. Polio survivors were the only big enough group that could say "Hey. We are people. We have rights too."

Polio hospitals weren't just for polio cases. It included different disabilities, crippled children or whatever they called it back then. Polio was the highest of the pecking order because you had PT care. Polio was unlike the spinabifida groups which also had brain involvement where their thinking processes were affected.

The polios were always the sharpest, the most driven, and kind of ran the hospital. Polio can affect certain parts of the brain but later studies that looked at cognition and memory in polio survivors compared to other individuals is the same. Pretty much everyone gets forgetful as they age. You can't blame that on polio. It's best when you control pain and fatigue. Anyone who is tired isn't thinking clearly. Polio people are still just as sharp as anyone else, even now with PPS.

The fact that polio doesn't affect cognition, it only affects mobility, made it really a unique disability group that really could push. A lot of you are very smart and very accomplished and very driven. That polio personality that developed has really been able to change society. That is a huge contribution.

Polio survivors aren't the only group that has banded together when they have something that is not common or doesn't get medical attention, but it is probably the biggest group of people. They have the biggest support network that developed when PPS started to appear and there weren't answers. There really is no other consumer group that has done what the polio survivors have done with PPS.

Polios made a huge difference with society and how society views disease and disability. In medicine it was the first time a virus was identified that caused disease. Studying the polio virus advanced the whole field of virology – how viruses enter cells, how they reproduce, understanding structure of RNA and DNA, our whole genetic template – being able to do RNA sequencing, the base work for all genetic studies that continue to be done. We have come far in the area of genetics which looks to be one of the promising areas of medical research as far as in the future being able to cure or control diseases through genetic treatments. The study of the polio virus laid the groundwork for

a lot of that. Government involvement became key in control of disease. Government funding provided for the research needed for polio and since then other diseases and now funds genetic research. Government also became involved in vaccinations and working with the public to prevent disease. Immunization programs, World Health Organization (WHO) and Rotary have taken it a step further, trying to prevent a lot of the serious illnesses throughout the world. That all stemmed from the polio epidemic.

My specialty of Rehabilitation Medicine started in the 1940s when we had all these kids that came through polio and had so many different rehabilitation needs. They needed somebody to follow them over time and schedule surgeries at different points and oversee therapy. Veterans coming back from world war with various injuries and amputations were part of that as well. Rehab medicine really became established.

The public perception of a right to have medical care and that the care should fit you came out of that whole time period. Polio brought to the forefront the need for individualized care plans because no two polio survivors are the same. The same treatment for all was not doable. Each was a little different so each needed an individual plan of care. That carried over into many areas of medicine now where care is individualized and special programs exist.

Intensive care units came out of the ventilator wards, the iron lung wards for polios. The iron lung was one of many technologies developed because of polio. And from the iron lung we went to different sorts of external respirators and then the positive pressure ventilators and the portable respirators we have now. Polio epidemics with many children and adults requiring mechanical ventilation led to that.

PPS led the way for rehab medicine folks to realize that aging with a disability was a unique thing. It wasn't the same as aging with

no disability. PPS is unique in some ways because of the uniqueness of polio. We began to recognize that spinal cord injured patients or patients who had residual paralysis from other neurologic disorders age differently. Like polio, cerebral palsy or muscular dystrophy also occurs to people when they are younger. As those patients get older we've learned different changes accelerated aging, new weakness appearing much earlier than you would expect we see. The recognition that PPS was something different has benefitted other disability groups as well.

PPS was first recognized by some reports in the 70's but it was in the 80's that it became known. It started to make news media and research started. Some consortiums formed to talk about what was going on and try to define it and those sorts of things.

THE EXPERIENCE OF HAVING HAD POLIO:

The Polio Personality

Now we'll look at individuals and I want more input from people. I'll talk about what has been written about the experience of having polio, the experience that formed what we call "the polio personality". I did not have polio so I do not pretend to know more than you. But I have talked to hundreds of thousands of polio survivors over the past 16-17 years of doing polio clinic, so I do have some experience. People have different experiences because some went to hospitals, some were more involved in longer recovery periods than others, and so on. Plug in where it applies to you.

Polio was a significant life change. Unless you were an infant, you were healthy and active and then came down with this disease that basically impacted the rest of your life and the entire family dynamics. A lot of you are parents now. Think about having a healthy child and then all of a sudden this child is ill and needs surgeries and this type of thing. Siblings were impacted as well. Siblings felt that the polio

survivor got all the attention because they were the one that was ill. They felt sorrow and sometimes guilt for being not afflicted. Other times the polio kid was sent off and they kind of left the family. So, it totally impacted the entire family. I think parents today who have kids that develop autism probably have a similar experience.

As you were being rehabbed from polio, exercise and work were emphasized. Depending on the age, the more impact this would have on your life. The emphasis on the value of working hard and pushing through pain and not giving in played a big part in developing what we consider the polio personality – that kind of inbred need to push, to work, to overcome things.

Dr. Halstead in his chapter talks about certain virtues he terms the isolation virtues – strength, courage, independence, self-reliance, hiding feelings. America is a nation that emphasizes a lot of those virtues. The polio survivor got it above and beyond, which translates in life later on. You are more detached from your feelings. It's harder to be vulnerable or to ask for help, to even admit that you need help with anything. Often you are intolerant of any sort of weakness either in yourself or others. It's like, "you can work through that. Come on." So those are some of the things that also impacted personality.

Here's another aspect of that. Because of the way the body adapts to nerve loss and innervation in muscle with the reinnervation process, a lot of people made phenomenal recovery. As that reinnervation occurred in somebody who was completely paralyzed all of a sudden one leg comes back and starts to work. You're walking. It's like a miracle child. This is a very unique process to polio. We have very few other diseases that recover like polio. That really impacted life. You expected to get

better. If you worked hard you would get better. Society believed this as well ("this kid got better"). If you didn't get better, you were lazy or not good. Many people have poor understanding of physiology and how the body works but it was much worse back then. Now there's more public awareness. People can read and look things up. There was ignorance of people saying "Oh well, you must not have worked hard enough."

If there was residual disability you just denied it. "No, I don't. I'm fine." Society didn't accept disabled people. In those days we shipped them off to hospitals and hid them; we didn't want to see them. In order to survive in society you had to fit in. Because of the nature of polio you could function in society and that led to more disability denial. Of course, if you were left in a wheelchair you couldn't deny that you were disabled. But those of you who became ambulatory could hide the fact that there was anything different about you, and tried your best to hide any polio residual.

I think also just the whole experience of being either sent away, isolated, quarantined, leads to a lot of feelings of rejection or abandonment. I can't imagine sending a small child away to a hospital for months at a time where sometimes families never visited, sometimes it could be once a week, but often left alone. And then, in the hospital having kids you knew die, encountering death at that age, or as they got better and went home to sleep and you never see them again. Again being abandoned or left by your friend. Even the rehab hospitals were at fault because once your rehab was done they sent you home and never saw you again either. So here you are, where you may live for months or years and then "By". Suddenly that relationship ends. Because this happened most commonly during the childhood or adolescent years, it had a big impact on who you became as a person. • Q & A REPRINTED IN JULY 2012

Thanks to **San Francisco Bay Area Polio Survivors** for allowing us to reprint Dr. Vandenaeker's presentation. In July we will re-print the very informative **QUESTION & ANSWER SESSION**. © Copyright 2010 by Phyllis Hartke, SFBAPS. No parts of this report may be used in other newsletters, posted online, reproduced or transmitted in any form without prior written permission from SFBAPS. Please submit your request to phartke@aol.com.

Dr. Perlman is asking our help to prepare her presentation to us on May 20th. What topics you would like her to address? What you would like to ask her? Email Priscilla at prisofoc@aol.com or call her at 714-968-1675

Don't Forget!

May OC meeting will be at the
Carpenters' Hall
1916 W Chapman Ave
Orange

Across the Street from The McDonalds.

Special thanks all who have donated so generously to both support groups. There are too many donors to list. Please write checks to Polio Survivors Association and during the fund drive please mail them to Polio Survivors Association, 12720 La Reina Avenue, Downey, CA, 90242. All fund received will be evenly divided between the Rancho and Orange County Post Polio Support Groups.

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How to contact Rancho Support Group

The Rancho Los Amigos Post-Polio Newsletter is published as a joint venture with the Polio Survivors Association.

For additional information please call Richard at **562-862-4508**

Or email us:

Rancho PPSG@hotmail.com



How to contact OC Support Group:

Call us for information:

Marte Fuller **562-697-0507**

Marilyn Andrews **714-839-3121**

Newsletter co-editors:

Baldwin Keenan 949-857-8828

keenanwhelan@cox.net

Janet Renison 949-951-8613

renison@cox.net

Agenda ideas for PPSG of OC?

Please call Aleta at 949-559-7102 or email Priscilla at prisofoc@aol.com





Rancho Los Amigos Meetings

**JOINT May 20th MEETING
WITH OC GROUP**

Future Rancho SG Meetings

Sat. June 23rd

Contact Rancho Group for Info.

Note: PICNIC Sat. July 28th



Orange County Meeting

SUNDAY May 20th 2pm - 4pm

**Dr. Perlman from UCLA
on current PPS
research and care**

See Page 1 col 2

**NOTE CHANGED
MEETING LOCATION IN MAP BELOW**

Future PPSG of OC Meetings

- No OC meeting in June
- Saturday, July 14, 2pm - 4pm
Indoor Picnic and Sharing
- No OC meeting in August
- September 8 - 2pm - 4pm
HICAP on Medicare changes.

Due to remodeling work in Villa Park our May Meeting will be at the Carpenters' Hall at **1916 W. Chapman, Orange**. Park behind front building. Enter rear doors.

NOT TO SCALE

